

TESTIMONY ON ASSEMBLY BILL 185
BIRTH DEFECTS PREVENTION & SURVEILLANCE ACT

Before the Senate Committee on Public Health, Senior Issues, Long Term Care
and Privacy

March 5, 2008

Presented by:

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Good morning Mr. Chairman and members of the Committee. My name is Pamela Pfeffer. I am the Director of State Programs for the March of Dimes and a mother of three. Thank you for the opportunity to present testimony today on behalf of the March of Dimes in support of Assembly Bill 185, which would significantly enhance Wisconsin's current birth defects surveillance system.

The mission of the March of Dimes is to improve the health of babies by preventing birth defects and infant mortality. Birth defects are the leading cause of infant death in this country, as well as a leading cause of childhood disability. It is estimated that 150,000 babies are born with a birth defect each year in the United States, which is approximately 4% of live births. It is estimated that approximately 2,700 babies are born with birth defects in Wisconsin annually.

In addition to human costs, birth defects also have significant economic costs. Lifetime costs for a child with a birth defect range from \$140,000 to \$700,000. For example, the lifetime cost of one case of spina bifida is nearly \$300,000. In Wisconsin, the total lifetime cost to care for all children born with birth defects is over \$140 million.

By implementing effective birth defects surveillance, we can track the incidence of birth defects and identify communities and populations at higher risk. State-based birth defects surveillance systems assist health officials evaluate needs,

deliver services, and implement and evaluate prevention programs. Epidemiological research into the causes of birth defects is a critical step in the development of cost-effective strategies to prevent birth defects.

Unfortunately, Wisconsin's current birth defects surveillance system is inadequate. The current system prevents the linkage of the birth defects registry with other vital health-related databases, which leads to inaccurate reporting.

In short, changes are needed to make the current system more effective in the reporting, tracking and analysis of birth defect data. In order to prevent birth defects, we need to know more about what causes them... and in order to identify those causes, experts must have access to specific information such as frequency of birth defects as well as other causative factors.

A fully operational birth defects surveillance system under AB 185 would help to better track birth defect occurrences and build a more effective database to identify birth defect trends. Ultimately, an improved system would help increase research and prevention activities surrounding these special health conditions.

More specifically, Assembly Bill 185 – as amended by Assembly Substitute Amendment 3 – would make the following statutory changes to improve the effectiveness of Wisconsin's birth defects surveillance system:

- **Link the system with other health-related databases, such as vital record information, which is essential to a complete database and avoiding duplicate reporting;**
- **Include stillbirth data in the registry, which is critical to birth defects research; and**
- **Expanding the statutory definition of birth defect to include “malformations.”**

At the federal level, March of Dimes volunteers and staff successfully lobbied the U.S. Congress to create a National Center on Birth Defects Surveillance and Developmental Disabilities at the CDC, as well as other federal programs targeted at preventing birth defects. The CDC is working with the states to carry out this effort. Assembly Bill 185 would help meet that goal by insuring Wisconsin’s registry is more comprehensive, accurate and complete.

The March of Dimes would urge you to support AB 185 as amended and help enhance birth defects surveillance in Wisconsin.

Thank you.



WI Birth Defects Prevention & Surveillance Act

Assembly Bill 185

TO: Senate Public Health, Senior Issues, Long Term Care and Privacy Committee
FROM: The March of Dimes Birth Defects Foundation
DATE: March 5, 2008
RE: Please support AB 185 – The Birth Defects Prevention Act

Today, the Senate Public Health, Senior Issues, Long Term Care and Privacy Committee will hear Assembly Bill 185 – The Birth Defects Prevention Act. This important legislation, recently approved by the Assembly would significantly improve Wisconsin's current Birth Defects Prevention and Surveillance System and ultimately help reduce the rate of birth defects in Wisconsin.

The March of Dimes Birth Defects Foundation would urge you to vote in favor of AB 185 – as amended by Assembly Substitute Amendment 3.

Wisconsin's Birth Defects Prevention and Surveillance System (BDS) was established in May 2000 to create a confidential birth defects registry comprised of birth defects found in infants and children treated in Wisconsin. Physicians and pediatric specialty clinics are required to report birth defects information to the BDS Registry, which is used to develop preventative strategies to decrease the occurrence of birth defects.

Unfortunately, Wisconsin's current BDS registry is inadequate and creates obstacles that make it difficult to collect accurate information, which is necessary to track and identify birth defect trends. Assembly Bill 185 will eliminate many of those obstacles and provide scientists and researchers with more precise information to study the occurrence and causes of birth defects. More specifically, the bill makes the following changes:

- **Expands the BDS registry to include stillbirth data and vital records information.** This data is critical to the accurate identification and scientific investigation of birth defects incidents and their ultimate prevention.
- **Expands the definition of "birth defect" to include malformations.**
- **Enhances protections to guard the privacy and confidentiality of information included in the BDS registry.**

Once again, the March of Dimes Birth Defects Foundation would ask you to support AB 185 – as amended by ASA 3. The legislation will help physicians and scientists identify the causes and ultimately prevent birth defects, which impact approximately 2,700 children in Wisconsin each year.